

# Diabetic Patients 'Perception of Their Relationship with Family Caregiver and Health-Care Providers: A Qualitative Study in the Diabetes Centre of the National Public Health Institute of Côte d'Ivoire

**Marie Laurette Agbre Yace<sup>1,3</sup>, Kadidiatou Raissa Kourouma<sup>2</sup>,  
Yvonne Tano-Kamelan<sup>3</sup>, Daouda Doukoure<sup>1</sup>**

<sup>1</sup>Groupe de recherche en nutrition et maladie métaboliques de l'Institut National de Santé Publique de Côte d'Ivoire BPV47 Abidjan Côte d'Ivoire; <sup>2</sup>Groupe de recherche en Politiques et Système de Santé de l'Institut National de Santé Publique de Côte d'Ivoire BPV47 Abidjan Côte d'Ivoire; <sup>3</sup>Cellule de recherche en Santé de la reproduction (CRESAR-Cl).

## ABSTRACT

**Objective:** This study aimed to investigate diabetic patients' perceptions of their relationship with healthcare providers and family caregivers.

**Methods:** This qualitative study using semi-structured questionnaires was performed from February to April 2018, in the Diabetes Centre of the National Public Health Institute. Data were subject to thematic analysis. Data saturation was reached after 49 interviews.

**Results:** the majority of the patients reported having good relationship with family caregivers and the healthcare team; actors they consider important in the management of their diabetes. The main factors that can improve the involvement of the couple patients/family caregivers were: good reception, more information and diabetes education, short waiting time.

**Conclusion:** family caregiver, diabetic patient and healthcare provider relationship is a necessary social dynamic for the diabetic patient: the keystone of the quality of care. It is important to make further for better decision-making in order to implement of a true winning partnership between patient, family caregiver and healthcare provider.

**Key Words:** Diabetes, Patient, Family caregivers, Healthcare services, Côte d'Ivoire

## INTRODUCTION

Diabetes is a growing public health concern. Indeed, according to the World Health Organization (WHO), in 2015, an estimated 1.6 million of death were directly attributable to diabetes<sup>1</sup>. Besides this chronic disease has an impact on the society, health system and individual affected by the disease.

Diabetes treatment is also part of a triangular relationship between family caregiver/patient/healthcare providers.

However, the relationship between these three actors has an impact on the quality and the continuity of care at home.

In the specialist literature different factors which influence compliance with the treatment have been identified such as socio-demographic characteristics and relationships with the disease, the therapy itself, family caregivers and healthcare providers<sup>2, 3, 4</sup>.

The healthcare provider-patient relationship is the factor with a stronger predictive power<sup>3</sup>. Indeed, this relationship

### Corresponding Author:

**Marie Laurette Agbre Yace**, Researcher Assistant, MD, MPH  
BPV47 Abidjan Côte d'Ivoire, Tel: 0022505 27 88 80; E-mail: agbreyace@yahoo.fr

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is an important concept in health care, especially in primary care. Numerous studies have found out that the relationship between healthcare provider and patient is often superficial and centered more on purely systematic and physiological aspects, without taking into account the patients' expectations, and making unilateral decisions, depending on their experience<sup>5,6</sup>.

However, it is established that actions need to be centered on the patient instead of being centered on the disease and the interests of the health institutions, thus providing integrated care<sup>7,8,9</sup>. The theoretical framework of the evaluation of the experience lived during the trajectory of care and services takes into account eight dimensions of the experience of care, based on the model of care centered on the patient and his family<sup>10</sup>. These eight dimensions are: respect for patients' values, preferences and needs (including involvement in decisions, listening, courtesy); access to care; coordination of care across different services; information, education and communication with professionals; physical comfort (including tranquility, cleanliness and safety, and pain relief); emotional support; the involvement of family and friends; transition and continuity of care<sup>10</sup>.

In Côte d'Ivoire where the prevalence of diabetes is around 4.94% according to the International Diabetes Federation (IDF), very little is known about the diabetic patient perception of family caregiver and healthcare providers. Thus, as part of the National Public Health Institute of Côte d'Ivoire (INSP) policy of continuous improvement in the quality of care for diabetic patients followed up at the Diabetes Center (CADA) who ongoing needs and are cared for at home by family caregivers; we performed this study with the objectives to understand in depth diabetic patients' views and experiences of their relationship with healthcare providers and family caregivers in the care-giving process.

## MATERIAL AND METHODS

The study utilized a qualitative approach centered on semi-structured interviews to assess diabetic patients' views and experiences regarding their relationship with health-care providers and family caregivers.

This qualitative research was part of a larger study on the family caregiver/diabetic patient/ health-care provider relationship, performed at CADA. CADA's mission is the outpatient management of diabetic patient, with an active line of more than 58,000 patients up to date. The centre receives in average 50 patients per day. The nursing staff includes twelve doctors, four nurses and one nurse aid.

The study was conducted from February to April 2018. The questions of the interview guide asked during the interviews were based on a review of the literature<sup>11</sup> and objectives were

focused on the patient' views and experiences with their family caregivers and health-care providers. The interview guide was pre-tested on a sample of 10 patients and this helped us to improve its content.

The patients were chosen at random and the interviews were conducted face to face by 3 researchers. Each interview lasted 30-45 min and was tape-recorded. Informed consent was sought before each interview. Participants were informed about the aim of the research project and what participation in semi-structured interviews meant. They were all informed that the participation was voluntary and that confidentiality would be secured throughout the research process.

The semi-structured interviews data were analyzed following recommended guidelines for qualitative research. Data collection and data analysis were carried out simultaneously. The researchers transcribed all of the interviews immediately after completing them. The data collected from interviews were transcribed in their entirety, coded and analyzed using a content and thematic analysis of the transcripts<sup>12</sup>. Data saturation was reached after 49 interviews.

## RESULTS

Of the 49 patients who consented to be interviewed, around two third were women and only 19 had the help of a family caregiver. The age range was 35–75 years: patients aged between 40 and 49 years were the most numerous. Regarding the socio-professional category, the majority of the participants exercised a liberal profession followed by the unemployed and civil servants. (Table1).

The data analysis resulted in the identification of three main themes with corresponding sub-themes related to the diabetic patients' perception of their relationship with healthcare providers and family caregivers: (1) Family caregivers as key actor for the diabetic patients; (2) Relationship with health-care providers between paternalism and effective communication, (3) Facilitators for a better involvement of the couple diabetic patient/ family caregiver in the care-giving process. Table 2 presents an overview of the main themes together with their corresponding sub-themes. Data used to illustrate the findings are verbatim quotes which have been altered as little as possible to retain authenticity, while maintaining anonymity.

### Family caregiver as key factor

In general diabetic patients declared having good relationship with their family caregivers and this theme emerged from the diabetic patients' descriptions of how they perceived their relationship with their family caregivers, and is illustrated by the following subthemes: help in following treatment (medicines, diet, physical activity), help in translating the instructions given by the health-care providers, financial support.

### **Help in following treatment**

All participants receiving help from a relative stated that they are very helpful in treatment adherence. One diabetic patient expressed it as follows: "My wife helps me a lot, she is strict with me concerning my diet, she always reminds me for my medicines and she encourages me do to some physical exercise, she even comes with me when I am walking" (diabetic patient 43).

### **Help in translating instructions**

Moreover, family caregivers are useful for patient who does not speak French. Family caregivers can translate into dialect the instructions and information given by the healthcare staff. Many diabetic patients emphasized this essential aspect, as illustrated by one of them: "I did not go to school, so French is not easy. It is my son there who accompanies me. When the doctor talks, he explains it to me in our dialect and then I understand" (diabetic patient 31).

### **Financial support**

Nineteen diabetic patients also mentioned the financial support of their family caregivers. Of them, one reported a situation where his daughter had an unpleasant behavior towards him because of the financial support she provides: "It is my daughter who accompanies me to my appointments, when we are sick we see everything. Some day we came for my appointment and the doctor said that I had to amputate my toe, when we finished my daughter got upset saying she was tired of spending money for my treatment. That day, I really hurt" (diabetic patient 13).

### **Relationship with health-care provider: between paternalism and effective communication**

This theme emerged from the diabetic patients' descriptions of how they perceived their relationship with the health-care providers. The corresponding subthemes were: effective communication, health provider as a figure of authority.

All the participants highlighted the importance of the health-care providers and the key role they play in the evolution of their health. It was a statement that we found frequently during the analysis of the interviews. However the quality of relationship depends on the health-care providers approach.

### **Effective communication**

Forty one participants stated that their health-care provider has established a good relationship with them. One of them reported it as follows: "My doctor is very kind with me, he knows how to talk to me, so that I do not stress too much about my illness. When I come to consultations, he takes his time to listen to me, I feel very important and cared. He even has my daughter's phone number and he often calls her to check on me." (diabetic patient 02).

### **Health-care providers as figure of authority**

Nine diabetic patients described the relationship the health-care provider has established with them as paternalist and still perceived health-care providers as a figure of authority as stated by one of them: "when I come to the consultation, our discussions are limited to instructions for treatment. Doctors know the right medicines to treat us. We do not know anything about diabetes we should follow their instructions. They know their job and we do not have to quarrel or argue with them" (diabetic patient 07).

### **Facilitators for a better involvement of the couple diabetic patient/ family caregiver**

This theme reflects on the facilitating factors that can reinforce their implication in care-giving process and their collaboration with the healthcare staff. This is described by the following three subthemes: healthcare provider's related factors; CADA organization related factors; healthcare financing related factors.

### **Healthcare provider's related factors**

All the participants emphasized the importance of a good reception by healthcare provider as illustrated by a patient: "when we come to the hospital and we are warmly welcomed, respected and doctors listen to us, there is no reason not to get involved" (diabetic patient 01)

The vast majority of the patient also deplored the lack of information on diabetes, as stated by one patient: "As far I am concerned, it will be easier for my family caregivers and me to get involved if we know everything about the disease. We must be at the same level of information. Doctors should give us more information on diabetes" (diabetic patient 44).

### **CADA organization related factors**

For many diabetic patients the organizational practices of CADA should be improved regarding appointments management. One diabetic patient described a situation where he argued with the healthcare provider: "Some day, I came for my appointment but the doctor came late, I got upset because it's not normal. We are sick and we are the ones to come early. Doctors must come early to take us quickly" (diabetic patient 20). "

Another factor was the waiting time which is too long according to the diabetic patient interviewed as stated by this patient: "When we come here, we can wait one hour or more before being received by the healthcare provider, it is very difficult for us. Sometimes we need to eat, but we cannot go outside to look for food by for fear of missing the appointment" (diabetic patient 15). "

## Healthcare financing related factors

Ten of the diabetic patients declared that the reduction of the treatment cost can improve their implication in the care process. One of them expressed it as follows: "We have so many medicines and medical examination that sometimes it is not possible for me to respect my appointment. The treatment is too expensive, if the government finds a solution to reduce the cost, my wife and me will get more involved in the care process (diabetic patient 22).

Moreover, three diabetic patients also cited the availability of medicine such insulin as a facilitating factor as mentioned by one of them: "How do you want my family caregiver and me to be involved when diabetic medicine are not available (diabetic patient 19). "

## DISCUSSION

### Strengths and limitations of the study

The limitation of our study is linked to the interviews' setting. Indeed, the interviews took place in CADA which may have induced a refusal to answer or generated social desirability response bias that is difficult to interpret.

The strength of our study consists in its originality and the context. CADA medical team is desirous to establish a strong family caregiver/diabetic patient/ health-care provider partnership. To succeed in this partnership, it is important to know in depth the patients view and expectations about the relationship they establish with healthcare providers and family caregivers. To this end, it is essential to develop study in proximology within CADA. The originality of this new area of research is to consider the role of healthcare provider and family caregiver as determining factors in the patient's environment, and therefore the effectiveness of the disease management and care<sup>13</sup>.

### Comparison with existing literature

Our findings showed that diabetic patients interviewed have in general a good relationship with their family caregivers and the health-care providers working at CADA.

Family caregivers are the backbone of healthcare system, and they are more and more involved in the care-giving process. In our study, the patients declared that family caregivers play an important role notably in helping them to follow the treatment, to translate instructions given by the healthcare providers from French to dialect. They also give a financial support which is essential for the adherence to treatment. The importance of family caregivers, especially during consultations, was also highlighted by Fanzang in French oncology patients<sup>14</sup>. However the presence of the family caregivers can be constraining of stressful<sup>15</sup>. In our study only one diabetic patient related a situation where his daughter who accompanied him misbehaved towards him. The nature of

the relationship patient/family caregiver can have an impact on the quality and the continuity of care at home, it is important for the healthcare providers to be attentive, listen in both patient and family caregiver.

As regard diabetic patient/health-care provider relationship, the majority of diabetic patient declared to have a good relationship with them and effective communication. Health-care providers should have effective communication with their patients in order to improve patient health outcomes<sup>16</sup>. However we noticed some health-care providers still establish paternalist relationship with patients.

In our study we did not explore the perception of the patient concerning the impact of poor relationship patient-physicians on the care-giving process. However in the study we conducted among health professionals in CADA, these declared that a poor relationship with diabetic patient could lead to the abandonment of the health structure and care<sup>17</sup>.

Moreover, a study carried out in China which investigated how aspects of the patient-physician relationship are associated with diabetes-related distress, insulin adherence, and glycemic control, showed that: patient dissatisfied with aspects of their interactions with physicians, exhibited poor insulin adherence<sup>18</sup>.

On the other hand, the qualitative study performed by Beverly and colleagues highlights the fact that both physicians and patients often assumed responsibilities for poor clinical outcomes in the treatment of type 2 diabetes. Patients felt defeated, depressed and expressed lack of self-efficacy, while physicians pointed to health system constraints and high expectations<sup>19</sup>.

Numerous studies have shown that patients prioritize the relational qualities of their caregivers<sup>19,20</sup>. In our study, relational qualities (listening, respect, kindness, hospitality) were cited by patients as one of the factors that facilitate their implication as well as that of their family caregiver in the care-giving process. In addition to this facilitator, the information and education of patients and family caregiver, the reduction of waiting time were also cited. For best patient outcomes, it is essential that patients have a more active role in their care<sup>20</sup>. When patients work in partnership with healthcare providers: complications decrease and care is better. Additionally, physicians' perceived responsibility and patients' self-blame for difficulty achieving treatment goals may serve as barriers to an effective relationship. Physicians and patients may benefit from a greater understanding of each other's frustrations and challenges in diabetes management<sup>19</sup>.

### Implications for future research and health-care providers practices

The establishment of a positive and trusting therapeutic relationship with patients and family caregivers is recognized as

an essential component of healthcare providers practice and is important for effective care. It is crucial for healthcare providers of CADA to use a framework to develop therapeutic relationships with the couple patient/family caregiver. It also important in clinical practice, to explore and understand the challenges in developing effective therapeutic relationships with patient at the healthcare system level, and considers how these challenges can be addressed through the implementation of proximology study<sup>13</sup>.

## CONCLUSION

In healthcare system, the key to any successful patient health outcomes is the recognition of the inseparable partnership between the couple patient/family and health professional. There is a need for decision makers to recognize the importance and the impact of this partnership on the quality of care. It is also crucial for health professionals to ensure that they work together with the couple patient/family caregiver, to establish effective communication and to pay attention to their needs in order to improve the quality of care.

## AUTHOR CONTRIBUTIONS

M.L.A.Y and K.R.K had the initial idea for this study and wrote the research proposal. K.R.K, D.D and Y.T.K conducted interviews: read, coded, and thematically analyzed the transcripts; and wrote the manuscript. M.L.A.Y and K.R.K reviewed and edited the manuscript. All contributors had access to the data and can take responsibility for the integrity of the data and the accuracy of the data analysis.

## Conflicts of Interests

Authors declare no conflict of interest

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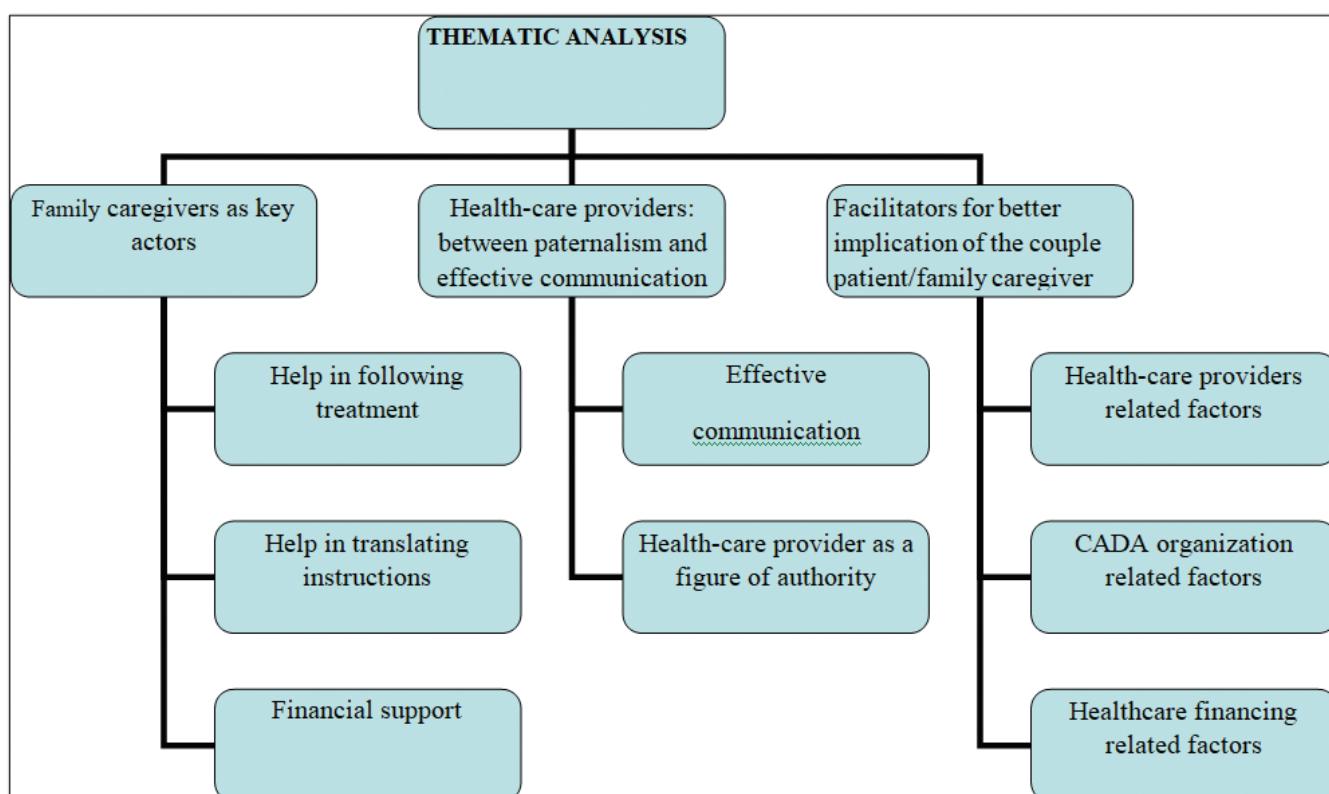
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**Table 1: Characteristics of the diabetic patients interviewed**

	<b>Frequencies</b>
Gender	
<i>Male</i>	18
<i>Female</i>	31
Age (years)	
<i>30-39</i>	5
<i>40-49</i>	17
<i>50-59</i>	13
<i>≥60 ans</i>	14
Help of a family caregivers	
<i>Yes</i>	19
<i>No</i>	30
Socio-professional category	
<i>Unemployed</i>	12
<i>Civil servant</i>	10
<i>Private sector</i>	4
<i>Liberal profession</i>	13
<i>Pastor</i>	3
<i>Retired</i>	7

**Figure 1:** Overview of main themes with corresponding subthemes in the qualitative content analysis.